

INITIATING END-OF-LIFE DECISIONS IN NEONATAL CARE – A CONVERSATION ANALYTIC STUDY

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SUMMARY POINTS BOX:

What is already known on this topic?

- A high proportion of neonatal deaths during critical care occur after conversations between doctors and parents about limiting life sustaining treatment
- Previous research has used post hoc interviews or questionnaires which may be confounded by the process.
- The trajectory of these conversations has not previously been directly studied

What this study adds:

- We recorded interactions about limiting life supporting treatment in order to evaluate the strategies used by doctors in initiating these conversations
- Conversations which provide parents with options for care are more successful in promoting alignment between doctor and parents, compared to conventional use of recommendations or best interests arguments.

Title: Communication in end-of-life decisions in neonatal care

ABSTRACT:

Objective: To understand the dynamics of conversations between neonatologists and parents concerning limitation of life sustaining treatments.

Design: Formal conversations where the baby was considered at high risk of dying were transcribed in detail, anonymised, and analysed according to the conventions and methods of Conversation Analysis.

Setting: A single tertiary Neonatal Intensive Care Unit.

Participants: Consultant neonatologists and families.

Main outcome measures: We developed a coding scheme for conversations based on initiation of the decision point and on the parental responses.

Results: We recorded formal conversations for 31 families from which sixteen conversations about limiting life support took place among nine families and six neonatologists. Five discussions concerned *withdrawal* of ongoing life-support; eight concerned *withholding* treatment in the future, and eight concerned “*do not resuscitate*” orders. We identified two strategies adopted by neonatologists: ‘making recommendations’, in which they put forward one preferred course of action (9 cases), and ‘providing options’ or choices, in which they not only list different possible courses of action, but also may employ other features such as deferring decisions to provide opportunity for contemplation (6 cases). Our conversation analysis-informed coding scheme was based on the opportunities available for parents to ask questions, and their expression of preference. Response scores for parents presented with ‘options’ (mean 5.3) was significantly higher than for those parents presented with ‘recommendations’ (mean 3.3; $p=0.008$).

Conclusion: Encouraging different approaches to conversations about limitation of life supporting treatment in neonatal critical care may lead to better parent engagement and less misalignment between the conversational partners.

INTRODUCTION

Introducing the concept of limiting treatment options to parents of newborn babies is one of the most difficult and challenging conversations in medicine. The degree of sensitivity and compassion required exceeds even those situations in adult practice where patient directives are being discussed. Such conversations are not uncommon in practice – 60-80% of deaths in neonatal units involve such decisions¹ and among babies born <27 weeks of gestation admitted for neonatal intensive care in England during 2006, 76% of 580 deaths were described as ‘planned’, and thus it can be inferred that death followed conversations about limiting treatment.² Such decisions are rarely based upon certainty, but on the interpretation of risks of death or survival with significant disability.

Neonatologists may use a variety of approaches to parents, based for example on concepts of parental autonomy or of paternalism, but the consequences of these individual approaches are rarely debated in practice or studied. The UK Department of Health recommends “clinical care decisions, including end-of-life decisions, are made by experienced staff in partnership with the parents and discussions held in an appropriate setting”.³ Professional guidance encourages the use of “team recommendations” and the concept of “best interests”.^{4,5} How this is applied in practice – relating to the baby alone or the family in a wider context – has not previously been studied. Although the clinical team usually initiates the conversation on the basis of their agreed decision preference, these guidelines also raise questions about the prior opinions of the clinical team themselves, which may vary widely,⁶⁻⁸ and the impact of individual attitudes about outcomes. In the wider context of neonatal care, parents report that they want to be involved in decision-making but that current involvement is less than optimal,⁹ suggesting that interpretation or implementation of the guidelines is varied.

Most research in this specific area is confounded by retrospection, using data gathered through remote interviews.¹⁰ This methodology may be less useful in understanding the measure of alignment between doctors and parents in the acute situation, because data are collected after the event and are influenced by the actual outcome. We therefore undertook a study based on

audio recordings of end of life discussions, using conversation analysis to evaluate the technical aspects of decision-making communication between doctors and parents. Our aim was to determine how doctors engage/facilitate informed parental involvement in the decision-making process, and which strategies are more or less effective in ensuring the smoothest progress through this conversational 'landscape'.

PARTICIPANTS AND METHODS

Families were recruited from a level three neonatal unit in England from July 2013 to April 2014. Following informed consent to record conversations from each consultant neonatologist, parents were approached for recruitment if they had a critically ill baby, and where a discussion around the redirection of care was a possibility in the future. Parents were introduced to the study by their consultant and subsequently recruited by CS who provided further information and obtained informed consent. We recruited 31 families in total, from which we identified specific conversations about the limitation of full intensive care and redirection to palliative care.

The research team were supported by a parent advisory group, who reviewed the protocol and parent facing materials, and advised on our approach and the potential for incorporating the findings into training courses. The group comprised parents who had similar experiences during intensive care and representatives of interested charities, namely Bliss, Sands, Together for Short Lives and Child Bereavement UK, and met on five occasions during this study. The parent advisory group commented on the findings of the study and contributed to dissemination of the results.

Formal conversations between doctors and parents were recorded; these recordings were anonymised then transcribed in detail according to conversation analysis (CA) conventions that represent aspects of speech production and timing (including prosody, silences and overlapping talk).¹¹ The recordings were subjected to CA, a technique that has been increasingly applied to medical interactions^{12,13} to investigate the patterns of interaction associated with particular

phases or activities (for example: patients' opening problem presentations,¹⁴ doctors recommending treatment¹⁵), in order to identify which communicative practices may be more effective than others.¹⁶ Accordingly, decision-making sequences during our recorded neonatal conversations were analysed in terms of the systematic ways through which decision-making was initiated by doctors, as well as the implications this had for how parents responded, and how different initiations either facilitated or inhibited parental involvement in this process. Recordings were made available to the parents in line with recommended practice.¹⁷

To provide a summary of the conversation analytic findings we devised a scale based on our observations of the parent's response: opportunity for further questions (only challenging questions asked, no invitation/no challenges, questions invited) and preferences expressed (strong disagreement, passive acceptance, freely asserted preference or concurrence with consultant deferral). We summated these two categories to provide an overall 'response score', the purpose of which was to describe the extent to which different strategies for presenting limiting life support decisions, has implications for parental participation in decision making (Table).

The study received approval from the East London Research Ethics Committee, and Research and Development approval from the participating NHS Trust. The study was funded by a Programme Development Grant from the National Institute for Health Research and a project grant from Sands. The funding bodies played no part in the conception, design, analysis or preparation of research outputs.

RESULTS

Of the 16 conversations, five discussions concerned withdrawal of ongoing life-support including mechanical ventilation; eight concerned withholding treatment in the event of further deterioration, and eight concerned "do not resuscitate orders".¹⁸ Some conversations included more than one type of decision. Of the babies who were subject to these decisions, three had

severe perinatal hypoxic ischaemic encephalopathy, four involved neurological complications following extremely preterm birth and one baby was born with a severe congenital anomaly. The parents were from mixed ethnicity (three White, five Black African/Caribbean, and one Bengali family) and mixed religiosity (six with Christian beliefs, one Muslim and two not declared).

Conversation analysis revealed that doctors initiated decision-making sequences in two main ways: 1) 'making recommendations', in which they formulated one preferred course of action, and 2) 'providing options' or choices, in which they not only list different possible courses of action, but also may employ other features such as deferring decisions to provide opportunity for contemplation. For a detailed analysis of the interactions see Shaw et al.¹⁹

In 'making recommendations' sequences, a one-option proposal to move from intensive to palliative care was presented. Doctors built their case for this preferred course by presenting evidence to set up the action as rational and optimal, and frequently invoked a previously agreed team perspective. This led to a recommendation posited as a robust conclusion,²⁰ rendering any alternative perspective a challenge to the doctor or team. Overwhelmingly, the recommendation was described as 'being in the baby's best interest', thereby confirming that opposition to the proposed action is a challenge to professional opinion. We observed that parents frequently responded with robust challenges (for example "*so you're telling me to kill my baby*"), which recurrently resulted in derailing the progression of the conversation due to misalignment between doctor and parent(s).

In contrast, option listing sequences comprised doctors providing options other than continuing intensive care, offering all pathways as favourable rather than pushing one as a recommendation, usually through the use of conditional "if-then" formats. No attempt was made to propose what the babies best interests were with certainty when outlining the decision that was to be made. Doctors therefore acknowledged the parents' involvement in the decision without specifying what their own perspectives or preferences were. This strategy

opened up the opportunity for questions, again foregrounding parental involvement in the process. Furthermore, doctors acknowledged that the decision would be 'difficult' with no clear solution. The decision was also on occasion deferred, with no interactional pressure to provide an immediate answer.

Recommendations were more frequent in the conversations, there were 9 recommendations and 6 option listing sequences across the conversations. All bar one of the recommendations were presented as a team opinion and said to be in the child's best interests. In the exception the conversation was subsequent to a previous conversation in which opinion and best interests were prominent. In four of the five conversations where an option strategy was used, no clinical opinion was expressed and the concept of best interests was not invoked. In the one that included a reference to best interest, it was presented as the opinion of the night team and not necessarily that of the counselling doctor.

We observed differences in the way parents responded to these alternative designs. In recommendation sequences, one decision was freely given, three were passively accepted (one subsequently deferred by parents), and in five strong resistance to the recommendation occurred. In contrast, in option listing sequences, four freely gave their preference about the end-of-life decision and two were, from the beginning, invited to go away and think about it. Using our coding system, we calculated a response score, based on the opportunity for parents to ask questions and to state their preference. Response scores for parents presented with 'options' (mean 5.3; 95% confidence interval 4.5-6.2) was significantly higher than for those parents presented with 'recommendations' (mean 3.3; 2.4-4.3; *Mann Whitney U Test: p=0.008*). Response scores did not vary significantly according to whether they were first or subsequent conversations about reorientation of care ($p= 0.508$), implying it was the strategy that guided the conversation as opposed to the preparedness of the parents.

DISCUSSION

Our study has taken a unique approach to evaluating the implications of conversations about end-of-life decisions. Through conversation analysis of recorded discussions, we identified two broad strategies – making recommendations and providing options – that led to different conversational trajectories and scales of alignment between parents and doctors. These findings have implications for guidance and training of professional staff in this area.

‘Recommendations’ were characterised by reference to a robust, corroborated team decision, and one that should be made in the best interest of the baby. Such a strategy adheres closely to current guidance, yet analysis revealed negative implications for parent participation in the decision-making process, resulting in either misalignment between parties or passive acceptance. Key here is offering the parent choice to begin with, because once a recommendation has been stated, the parent is placed in the position of having either to accept or reject the recommendation, with the implication that a rejection challenges the medical opinion. Such resistance in response to recommendations has been found elsewhere in decision-making sequences.^{21,22} In short, the use of recommendations invoked little evidence of collaboration, patient-centeredness, or shared decisions.

In contrast providing options was characterised by various approaches: an orientation to joint decision-making, the construction of the action as a plan rather than a decision, the provision of information that did not explicitly favour a particular outcome, the listing of options rather than recommending a single course of action, and finally, in some cases, deferring the relevance of a decision from the immediate interaction at the start of the conversation. The implications of this approach for parental participation were quite different, including strong alignment between parties where parents were able to assert their preference without misalignment with the doctor, and avoiding simply acquiescence to professional judgement.

By deferring the decision, the doctor makes other actions possible as responses, rather than putting parents in the position of having to accept or reject unilateral recommendations.²³ The

parents are invited to present their decision-preference in the future.²⁴ This enables and encourages parents to seek clarification and explore uncertainties without needing to challenge the doctor (or whole team) about their preferred option.

Whilst much research has involved interviews to explore the perspectives and experiences of doctors and parents in neonatal decision-making,¹⁰ systematic research into the actual process of decision-making is limited. Studies that have been undertaken have used methods such as ethnography to observe decision making practices on the neonatal unit and have identified widely contrasting approaches from full parental autonomy to medical paternalism.^{25,26} A recent survey of practice throughout Europe highlighted the lack of parental involvement in developing guidelines around decision making at preterm birth.²⁷ Although these studies consider parental involvement in a broad sense, in this study we have systematically evaluated parental involvement by recording the conversations between the doctors and the parents, and analysing in detail how and when the talk is produced, moment-by-moment, through the detailed analysis of decision-making as it happens. This allows us to then explore the implications for alternative approaches to the decision-making conversation by doctors in terms of what the parent actually does next.

The broader medical communication literature in adult practice has gone some way to providing an evidence base for shared decision-making practices, based on recordings of actual consultations. Coding systems used to measure the decision-making process are typically developed from theoretical perspectives around decision-making, as well as patient and health care professional perceptions. However, whilst coding enables retrospective identification of aspects of talk that might be regarded as important, less attention is paid to the social organization of decision-making conversations in an inductive manner. Conversation analysts, in contrast, have demonstrated the importance of analysing actions such as decision-making within the interactional context in which they are produced,^{28,29} rather than pre-characterising them.¹²

Limitations

Whilst we have demonstrated clear patterns within and across conversations, the data are based on a relatively modest number of recordings in one centre. We are currently collecting further conversations from a different centre to further validate our coding tool and explore any alternative decision initiation approaches from other doctors.

Implications for parents

Conversations concerning potentially limiting treatment remain some of the most delicate and difficult a parent may have to participate in for their child. Introducing the opportunity for decision-making in a way that invites parent participation is essential to allow parents to explore their opinions. We have defined practices through which doctors can maximise this participation. The notion of 'best interest' (when the alternatives are all unpalatable) may put parents in an invidious position of choosing between their own interests and feelings and those of their baby, given that their baby's 'best interests' might not match theirs. Parents require time to carefully explore their position within the context of their unique family circumstances, alongside clinical information and uncertainty, this usually being the nature of this decision-making environment. By exploring alternative options, parents may be supported in adjusting to the decision. This could be important in long-term adjustment to their loss or to the evolution of impairment as their child develops. Parents have to live with the decision they make, so giving them such interactional opportunity is important.

There are certain clinical scenarios where using 'best interests' as a strategy may seem obvious, for example where death appears to be inevitable for the baby and a managed end of life strategy may be considered preferable to prolonging intensive care. However, even here, there are always choices as to how death can be managed that provide options for parents to consider. In this study, exploring options facilitates the alignment of parental perspectives with those of the doctor. In contrast, the early use of recommendations does not invite parental perspectives and limits their options. Exploration of alternative options by parents in this situation may act as a challenge to what the doctor has proposed.

Implications for doctors

In discussions around the end-of-life, doctors are enjoined to use recommendations and a test of best interests.^{4,5} However, the framework as to how the best interests are determined remains obscure.³⁰ Where death is not inevitable (albeit still likely) the doctor has little decisional support to determine which outcomes represent “a life not worth living”.³⁰ Research based information may produce estimates of risk for extremely preterm babies, using, for example national cohort studies³¹ or a web-based risk estimator,³² but it is by no means clear which outcomes are to be weighed against survival, nor whether the professional concept of severe impairment or disability is sufficient to comprise “a life not worth living”. Doctors may bring their own biases regarding the impact of potential outcomes of impairment to these conversations,^{6,8} which may not accord with the attitudes of parents. Thus, by presenting pre-considered recommendations and assessments there is little opportunity for parents to consider an alternate course of action.

The RCPCH (2015) Framework for Withholding or Withdrawing Life Sustaining Treatment in Children, specifies that “...*The final decision should be made with the consent of the parents, though the clinical team must take the main responsibility for the decision. This can help to alleviate the burden of guilt that some parents feel.*”³³ In contrast, Anspach has argued that “...*a well-intended but paternalistic attempt to protect parents from guilt may, ironically, produce the very effect it is designed to minimize and may deter, rather than facilitate, vigilant information processing.*”²⁶ The encouragement of the use of recommendations and best interests arguments may thus actually alienate the very engagement that parents want in these situations.

Further implications

Having such conversations demands sensitive and well-planned strategies on the part of the doctor. Presenting options can invite parents to be more fully involved in decision-making, but this does not preclude the possibility of certain options being more persuasively presented.

Indeed, Quirk and colleagues show how decisions can be directed through discounting certain options that are listed.²² Exploring how options might be presented and thus steer parental decisions, provide for an interesting area of future study.

However, there is currently little uptake of formal training in communication among neonatal trainees³⁴ and training is locally developed, resulting in inconsistent educational delivery and content throughout the country. The assessment of communication during professional exams is inadequate to evaluate performance in these important conversations and the use of an 'apprentice' model to sign off ability to lead such conversations depends on the experience and understanding of the consultant trainer.

Furthermore, the conventional approach of using role-play scenarios as a training tool falls short of capturing the complexities and dynamics of the real life version, risking an enactment of what has elsewhere been systematically studied as an inauthentic representation of what actually happens.³⁵ What is missing from the literature is a strong evidence base for training to equip doctors and nurses with effective and sensitive communication skills. Without an empirical base, the chain from knowing what is effective, and what should be consolidated in the training manuals and protocols that underpin interventions, through to developing policy, is weak.³⁶

It is clear that our findings may be integrated into training. Facilitating doctors to be more cognisant of how they talk to parents and developing a toolkit of skills for practice may reduce stressors on doctors, who do find these conversations challenging. Thus, new approaches to training that integrate and explore the effects of different strategies in conversational practice among neonatal trainees and consultants would be of value, and likely to lead to better parent outcomes with less misalignment between the conversational partners.

3144 words

Table: Conversation analysis derived coding framework

Parental responses to the decision		Score
Opportunity for questions prior to making decision	Questions invited	3
	No questions clearly invited / not clearly challenging	2
	Questions as challenges	1
Expression of preference	Preference asserted freely with minimal resistance / concurrence with consultant deferral	3
	Passive acceptance	2
	Strong resistance	1
Total score		2 – 7

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